

EXPLORING HOPE IN FAMILIES AFFECTED BY PROBLEMATIC SUBSTANCE USE:  
AN INTERPRETIVE DESCRIPTIVE STUDY.

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for the Degree of Master of Nursing  
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## **Abstract**

The effects of problematic substance use are far-reaching and affect the individuals engaged in problematic substance use, as well as their family members. Hope is a powerful psychosocial tool for these families and caregivers and can reduce their suffering. When utilized in periods of hopelessness and despair, hope helps people to develop resilience. There is limited or no research on the experiences of hope for family members affected by problematic substance use. In this interpretive descriptive study, I explored the experiences of 21 family members concerning hope and hopelessness in their lives. Major themes I found included the manifestation, impacts of, and factors countering hopelessness. Overall, my findings show that family cohesiveness, social structures, and the interplay of hope and hopelessness are significant factors that determine hope for family members of people who experience problematic substance use. Appreciating the families' challenges gives health care professionals a better understanding of how to assist families in finding hope during uncertain and challenging times. Clinicians can assist families in identifying their strengths, agencies, and pathways of hope, which can support their self-care and enhance their resiliency. My personal and professional experiences as a Registered Nurses both informed and were shaped by this study. Specifically, this study has shaped my understanding of the role of hope in practising strength-based approached to care.

## **Acknowledgments**

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## **Dedication**

This work is dedicated to God Almighty whose love and protective hands have kept me all these years. My late husband, Dr. Kufre Udoh, who encouraged me to be the best that I can be in life. My mother, Alice John who died 3 months ago, I dedicate this work to her. My mother has been a pillar of strength all my life and taught me to be strong, determined, and always hopeful. I know she would be proud to read this work. My two handsome and wonderful boys who have supported me all these years through all kinds of challenging situations – this work is only possible today because of their support. I love you both so much. Your father would be so proud of all of us today.

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## Chapter 1: Introduction

Problematic substance use<sup>1</sup> is a global problem and in Canada, the economic burden of substance use is \$38.4 billion per annum, which translates to approximately \$1,100 per person in health care cost (Canadian Center for Addiction, 2018). Seventy percent of this cost is attributed to tobacco and alcohol and 30% to opioid use. In recent years, these costs have been rising especially for cannabis and opioid use. Apart from the preceding health care cost and the impact on physical health, problematic substance use affects mental health and wellbeing, engagement in school and/or work, as well as relationships of those who are affected by problematic substance use and their affected family members<sup>2</sup> (Government of Canada, 2019). Amidst the current opioid overdose crisis, caused by an unsafe drug supply, the concurrent methamphetamine outbreak, and the social acceptability and often invisible negative impact of alcohol use, families with members engaged in problematic substance use, must make meaning of the fatalities and morbidities associated with problematic substance use.

Over 1,900 opioid-related deaths and 17,050 opioid-related hospitalizations occurred in Canada between January 2016-June 2019 (Government of Canada, 2019). In 2014/2015, Saskatchewan, a Province in Canada, had the highest rate of hospitalizations for opioid poisoning of all the Canadian provinces, at the rate of 21 per 100,000 individuals, compared to

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<sup>1</sup> I have chosen to use 'substance use' or 'problematic substance use' through out this proposal. Using words such as 'addiction' or 'substance abuse' is often perceived as negative by those who use substance and seen as contributing to further stigmatization. 'Problematic substance use' refers to substance use that has negative consequences on a person's life and wellbeing, in other words, patterns of substance use interfere with a person's life (Government of Canada, 2018). Substance use can be related to alcohol or other drugs or can be process related and refer to things such as gambling or internet use. I use the term 'substance use' or 'problematic substance use' in the broadest way possible. Substance Use Disorder refers to "[t]he clinical term describing a syndrome consisting of a coherent set of signs and symptoms that cause significant distress and or impairment during the same 12-month period" (Recovery Research Institute, 2020, n.p.).

<sup>2</sup> Affected family members include intimate partners, parents, siblings, children, relatives, or close friends. This term also includes those directly affected by the family members' problematic substance use, who make key contributions to their lives (Gethin et al, 2016).

the rate of 13.4 of the national average (Canadian Institute of Health Information, 2016).

Between 2011 and 2015, 1.2 million needles which are 25% of all clean needles in Saskatchewan was distributed in the Prince Albert Parkland Health Region (Canadian Research Initiative in Substance Misuse [CRISM], 2018). As a result of this increase, the Government of Saskatchewan has resorted to the distribution of take-home Naloxone kits to prevent overdose (Government of Saskatchewan, 2015).<sup>3</sup>

Within Saskatchewan, the city of Prince Albert with a population of approximately 40,000 and servicing an area of approximately 78,000, is one of the many communities in Canada severely impacted by substance use (Fenno, 2016). The Community Mobilization Prince Albert's (CMPA) Hub and Center of Responsibility (COR), which is a multi-agency effort to develop interventions to prevent crime, indicated that there is an increasing number of referrals to treatment centers and an increase in youth arrest due to substance use in Prince Albert (Fenno, 2016). Fenno's study on Prince Albert's alcohol and drug use reveals that 33.8% of youth who live in Prince Albert use alcohol once a month or less, 23.1% use marijuana, and 29.8% binge drink, compared to the national average of 25%, 11.6% and 22.8% respectively. With 9.2% of all emergency room admissions and 18.2% of all hospital admissions attributed to substance use (Rossouw, as cited in Maina et al, 2017), Prince Albert is facing a substance use crisis that has stretched both family and health care resources. In recent years, Prince Albert has worked with great effort to address problematic substance use, including the development of a detailed alcohol strategy (Community Alcohol Strategy Steering Committee [CASSC], 2017).

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<sup>3</sup> Prince Albert has some of the highest rates of HIV cases in Canada (Leo, 2015), many of which are linked to Intravenous Drug Use (IDU). In addition, most clients on methadone treatment in PA have a history of IDU (Maina, Crizzle, Maposa & Fournier, 2019).

Though the statistics show the increasing use of opioids in the province, the CMPA's statistics of 2012/2013 indicated that alcohol made up 62% of the Hub discussions, making it the largest category of substance use in Prince Albert (CASSC, 2017). This finding was confirmed by the findings of a youth survey done in cities across the Province of Saskatchewan, Canada that showed that 67% of Prince Albert's grade 10 students reported binge drinking compared to 49.4% in the Canadian sample, 45% of police arrests were due to public alcohol intoxication compared to 17 in Saskatoon, 7% in Moose Jaw and 22% in Regina (CASSC, 2017). Due to this finding, the Community Alcohol Strategy Steering Committee (2017) developed a "Call to Action" to try to alter people's attitudes toward alcohol and develop a stronger and healthier community.

Families are an integral part of people's lives and problematic substance use by an individual family member can have significant impacts on the physical, spiritual, emotional, and psychological wellbeing of the other family members (Smith & Estefan, 2014; Smith, Estefan, & Caine, 2018). When a family system is placed under stress, like the stress caused by a family member with problematic substance use, all the family members will strive to restore the balance or maintain the stability of the system (Bradshaw, Shumway, Harris & Baker, 2013; Howard et al., 2010). Stress is aggravated by the perception that problematic substance use stigma is intertwined with criminality, causing a lot of shame and undermining self-worth (Corrigan, et al., 2017). To restore a balance, family members often engage in various stages of dysfunctional, maladaptive, or enabling<sup>4</sup> behaviours. These may include dishonesty, denial, or unconsciously or consciously overlooking the manipulative nature of the family member with problematic

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<sup>4</sup> We use the word enabling very carefully due to it is associated stigma. As pointed out by the Recovery Research Institute (2020), enabling refers to "[a]ctions that typically involve removing or diminishing the naturally occurring negative consequences resulting from substance use, increasing the likelihood of disease progression. The term has a stigma alert, due to the inference of judgement and blame typically of the concerned loved-one" (n.p.).

substance use (Howard et al., 2010). The stress and loss of equilibrium in the family system hold a significant psychological impact for affected family members. It calls forth a sense of disempowerment and constraints on their abilities to help the family member with problematic substance use (Orford, Velleman, Natera, Templeton, & Copello, 2013). While family members often play multiple roles in the lives of people with problematic substance use, the ability to empower family members to cope well with their caregiving role is rather challenging. It is important to recognize that hope has been identified as a key psychosocial element for affected family members (Duggleby et al, 2010). In this study, I explored the experiences of family members affected by problematic substance use with attention to their experience of hope and hopelessness (Miller, 2019).

### **The Context of this Study**

In this thesis, I draw on already collected data from a study entitled: *Exploring the needs of and developing resources for families affected by addiction in Prince Albert, Saskatchewan*. Dr. Geoffrey Maina is the Principal Investigator of the Study. The overall purpose of his study was to explore the experiences and needs of families affected by problematic substance use and to develop culturally appropriate and family-centred resources to address them.

### **Situating Families**

Substance use has been described as a significant mental and public health crisis in recent years (Ahmed and Stanciu, 2017; Darrodi, Younesi, Bahrami & Bahari, 2010). It impacts individuals from all walks of life (Khantzian & Albanese, 2008) as it affects health professionals, politicians, policymakers, high/low-income earners, the elderly, youths and all age groups. Family members of individuals affected by substance use often endure painful and stressful experiences (Conyers, 2009; McCann, Lubman, Boardman & Flood, 2017). Affected family

members require respectful and supportive services that reduce the stigma they experience (Haskell et al, 2016).

Despite such impacts, studies inquiring into the necessary support for families affected by substance use are rather scarce (Conyers, 2009). Although efforts have been made in recent years to acknowledge the role that family members play during the course of their loved one's problematic substance use (Copello & Orford, 2002), there are few resources to support family members in their self-care or caregiving role (Conyers, 2009; Orford, Copello, Velleman & Templeton, 2010).

### **Impact of Substance Use on Family Members**

Problematic substance use is a family disease (Bradshaw et al., 2015; Roth, 2010) with grave consequences on family members' health status (Ray, Mertens & Weisner, 2007; Weisner, Parthasarathy, Moore, & Mertens, 2010). Although often the harm done to family members is evident, it is difficult to calculate the magnitude of the impact (Orford et al., 2010). Affected family members are at high risk for shifting boundaries, roles, rules, and family dynamics that negatively impact the health of individual family members and the family as a unit (Bradshaw et al., 2015). Besides, family members are more likely to be diagnosed with their own substance use or depression, and they tend to have higher medical claims and costs (Ray et al., 2007; Weisner et al., 2010). Generally, in families where one or more members of the family engage in problematic substance use, have high levels of relationship dissatisfaction, instability, conflict, sexual dissatisfaction, and/or psychological distress exist (Kloesteman & O'Farrel, 2013). Other experiences like physical exhaustion, sleepless nights, anxiety, and emotional distress brought on by desperation and frustration are but a glimpse of their experiences (Bradshaw et al., 2015; Conyers, 2009; Rane et al., 2017).

Constantly haunted by questions, such as: ‘Where did I go wrong?’, ‘What if?’, ‘Could I have known?’ affected family members often experience fear, doubt, shame and guilt (Conyers, 2009). Besides, the impact on family members’ physical and mental health, their spiritual and emotional well-being is also affected (Darrodi, Younesi, Bahrami & Bahari, 2010). Family members experience maladaptive and antisocial behaviours, unemployment, poor mental health, sleep deprivation, domestic abuse, marital conflicts, and parental dysfunction (Akram et al., 2014).

### **Needs of Families Affected by Problematic Substance Use**

Family members are individuals, who are faced with the tremendous task of dealing with the stressful and unstable life circumstances of their loved ones living with problematic substance use. Families feel disempowered, often due to their inability to sustain contact with the person with problematic substance use (Nunes & Sani, 2013). As such, it has been found that affected families would benefit from greater support for self-care, support to develop a coping mechanism, educational information and emotional support to enhance their quality of life (Orford, Velleman, Natera, Templeton & Copello, 2013). In addition, hope has played a significant role in families’ lives.

Hope is seen as a way for families to regain control over their lives (Bradshaw et al., 2015). Hope in the context of substance use has been studied by researchers in the disciplines of nursing and psychology (Koehn & Cutcliffe, 2012). Most of these studies outlined how hope along with correlates like self-esteem and optimism, deterred youth from using substances, and how low levels of hope correlate to increased consumption of alcohol among adolescents (Wilson, Syme, Boyce, Battistich & Selvin, 2005). Published research on hope and family members have focused on the hope of family caregivers for people with chronic diseases (Parse,

1999), critical illness (Gelling, 1999; Chua Patel, 1996), sickle cell anemia (Forte, 1998), HIV/AIDS (Kylma, Vehvilainen-Julkunen & Lahdevirta, 2001), dementia (Irvin & Acton, 1997), palliative care (Borneman, Stahl & Smith, 2002; Holtslander, Duggleby, Williams & Wright 2005) and bereaved family members (Holtslander & Duggleby, 2009). Few studies exist that explore ways of supporting families affected by problematic substance use (Orford et al., 2013).

It is in recent years that attention has been drawn to the importance of supporting family members whose members use substances (Akram, Copello & Moore, 2014). Families provide physical, emotional, social, and financial support to family members who are using substances. Also, they are a vital anchor during difficult periods of dealing with problematic substance use treatment and periods of remission (Smith, Estefan & Caine, 2018). There is an urgent need to identify and mobilize families' inherent strengths and resources to build a strong network of healthy relationships to support their family member who uses substances.

### **Dealing with Problematic Substance Use**

Problematic substance use impacts family dynamics. It weakens communication and erodes trusting relationships within affected family members. According to the US Department of Health and Human Services, through their Substance Abuse and Mental Health Services Administration (SAMHSA, 2019) and the American Addiction Center, family members tend to play the following roles to cope: *The Hero or Saviour* – in this role family members end to compensate for the shame, guilt, and helplessness they feel around their loved ones. They live in denial and try to cover up for the person with problematic substance use by trying to make the person look good to people. Family members that assume the hero/saviour role may deny the need for professional assistance as they feel they can handle the situation. Family members assuming the *Mascot* role tend to provide some comic relief to the already hyper-stressed family

by using humour to deflect the hurt and minimize the pain they are experiencing. *The Lost Child* family members tend to suppress their feelings and avoid conflicts at all costs and try not to impose further challenges on the already limited emotional family resources. Often these affected family members suffer in silence, hiding physically and emotionally. *The Scape Goat* family members take the blame for everything and deflect attention from the individual with problematic substance use by creating other concerns and problems. *The Caregiver/Enabler Rescuer* tend to protect and insulate the individual with problematic substance use by excusing their behaviour by running interference or smoothing things out. However, to help their loved ones living with problematic substance use, their actions end up stunting the response to recovery for the person.

Despite all the grave consequences of problematic substance use on families, there is little to no support offered to them, the primary focus is on the individual with problematic substance use (Conyers, 2009). Many families mask their difficult experiences with the common belief that people who use substances have themselves to blame and that they could wean themselves from substance use if they had the desire to do so (Conyers, 2009). Proponents of this belief suggest that families of individuals using substances did something to necessitate the disease (Conyers, 2009). Affected family members who hold firmly to this belief are bound to a life of shame and stigmatization that keeps them from reaching out for help (Corrigan et al., 2017). Only in recent years has attention been paid to better understand how to support family members whose members use substances (Akram, 2014). Given that addiction is a family illness, (affecting both individuals with and without problematic substance use), there is an urgent need to reconsider addiction care, from individualized care directed towards the person who uses



substances, to also include affected family members. There is also a need to understand what sustains families, which has called for me to better understand hope in relation to caregiving.

### **Turning Towards Hope for Families Affected by Problematic Substance Use**

Hope is a vital concept in health care and is significant in nursing research (Hammer, Mogensen, & Hall, 2009). Even though hope plays a vital role in people's lives (Kim, Kim, Schwartz-Barcott & Zucker, 2006), there is significant difficulty in operationalizing hope and having a standardized definition of hope. There is no consensus on the definition of hope (Cutcliffe & Kaye, 2002; Herrestad, Biong, McCormack, Borg & Karlsson, 2014; Samson, Tomiak, Dimillo, Lavigne, Miles, Chowuette & Jacob, 2009). However, there's a consensus that hope is mysterious and elusive in nature, restoration of being and powerful life and society resource (Cleary, Sayers, Lopez, Shattell & Cleary, 2016; Duggleby et al., 2010; Miller, 2019; Reder & Serwint, 2009). A comprehensive definition of hope needs to consider the evolving reality of hope which is having both behavioural and cognitive dimensions and at the same time, intangible components of spirituality (Samson et al, 2009).

Farren, Wilken and Popsvich (1992, as cited in Samson et al., 2009) proposed a definition of hope that considers its multidimensional nature, its richness, as well as its complexities. According to these authors, there are four key components in the definition of hope, namely: an experiential process, a relational process, a spiritual process, and a rational thought process. Hope is experiential in the sense that individuals are solely responsible for charting the course of their own lives. It is a cognitive or rational process in that hope is lived through goals that need to be achieved and spiritual in the sense that hope transcends observable material reality. Finally, relational in the sense that hope is processed in relation to an individual's sense of connectedness with others.

Schrank, Bird, Rudnick and Slade (2012) undertook a systematic review of studies focused on hope and thereafter described hope as “a fundamental future-oriented expectation (illuminated by negative experiences) of achieving a personal goal which is meaningful and considered subjectively possible depending on the individual’s characteristics or personal traits (determination, resilience) and external variables (support from therapists, resources available)” (p. 555). The authors point out that hope has a negative correlation with depression, anxiety, family dynamics and unemployment and a positive correlation with self-esteem, self-efficacy, perceived recovery, social spirituality, quality of life, and empowerment. Chadwick (2015) supported Schrank and colleagues’ (2012) view by defining hope as a cautious future-oriented feeling (hope appeal), like the fear that drives behavioural patterns by directing an individual’s thoughts on future punishment and rewards. Hope is also defined as the best resource of an individual; whereby hope is constantly present internally. Hope for people with significant ill-health makes impossible things become possible (Lynch, 1974 as cited by Miller, 2019). In the context of chronic illness, Duggleby and colleagues (2010) define “hope as a transitional possibility found within uncertainties” (p. 1).

In Duggleby and colleagues’ (2010) meta-synthesis on hope for family members, the common finding in all the fourteen studies they reviewed, revealed that there is a turning point for family caregivers in the disease process. This turning point is marked by refocusing from a challenging present situation to a positive future condition; it begins with a belief in possibilities and a positive future, followed by a stage of transition and a stage of reality that is rooted in the present situation (Duggleby et al., 2010). The authors stated that amid the family members’ difficulties, there is a deep-seated belief that their situation and the affected family member will get better someday and that there is a possibility of a better future.

As the disease progresses with subsequent negative impacts, family members' belief becomes shaken, leading to a transitional phase in the hope process (Duggleby et al., 2010). In this phase, families explore hope's reactive and temporal nature (Bland & Darlington, 2002), hope's changing nature and fluidity (Borneman et al., 2002; Duggleby et al., 2010), and the unfolding and dynamic nature of hope (Kylma et al., 2003; Holtslander & Duggleby, 2009). Hope is never static. Hope is dynamic and as such, affected family members are always trying to refocus their lives to sustain hope. At times this means that they need to find new ways to cope.

As complications of substance use set in, family members often come to accept the reality that they must seek new coping mechanisms. Their hope at this stage is rooted in the present reality of their situation (Bland & Darlington, 2002). Often, they begin to take life one day at a time (Duggleby et al., 2010), learn to live in the moment as they are unsure of tomorrow (Holtslander et al., 2005), and learn to set realistic goals (Verhaeghe, van Zuuren, Defloor, Duijnste & Grypdonck, 2007).

Hope is about doing something, including doing a job, engaging academically, raising kids, caregiving with greater confidence and to move past some of the distress when defined in relation to recovery from problematic substance use (Kimball, Shumway, Austin-Robillard & Harris-Wilkes, 2017). This may include a positive tolerance for disappointment, setting goals and having the tenacity to pursue these goals despite all odds, and entertaining the possibility of rejuvenated confidence (Brown, 2013). Rebuilding confidence in oneself and an ability to deal with challenges that problematic substance use causes is vital to the wellbeing of affected family members as many tend to lose confidence in their situations due to the stigma and self-blame they experience (Kimball et al., 2017).

Bradshaw et al. (2015) see hope as closely linked to optimism, outcome expectancies, and self-efficacy while Chappell and colleagues (2015) observed that people with high hope levels often find multiple pathways to achieve their goals. Perceived success in achieving goals is often correlated with positive emotions and failure in goal achievement to negative emotions (Chappell et. al, 2015). To understand hope better, the relationship between hope and hopelessness must be understood.

### **The Interplay of Hope and Hopelessness**

Hope and hopelessness are powerful lived experiences that coexist in the human realm (Flaskas, 2007). The interplay of hope and hopelessness within close relationships and family ties can be very complex. Family and individual experiences of hope and hopelessness are embedded in historical and familial context and the wider social and community processes people live within (Flaskas, 2007). Hopelessness in challenging circumstances thrives when the future is certain, known, and bleak (Herrestad et al., 2014). It is important to recognize that “strong hope and strong hopelessness [can] exist side by side” (Flaskas, 2007, p.189). This resonates with addiction counsellors, who believe hope and hopelessness are constantly present, thus increasing the level of hopelessness will lead to an understanding of the current level of hope and vice versa (Koehn et al, 2012). Koehn’s interplay of hope and hopelessness is used in addiction counselling to assist adolescents to define these two concepts for themselves thereby moving them to a readiness phase where they can think and act from a place of hope. This too might be relevant for other family members.

### ***Types of Hope***

There are different types of hope to reflect its transitioning and future-orientated nature. As circumstances change, some affected family members’ hope is lost, while for some, new hope

emerges. It is important to recognize that all types of hope occur concurrently, never mutually exclusive to each other (Duggleby et al., 2010).

Concrete specific hope is described as task-specific hope and is akin to goals or outcomes. This kind of hope includes lost, new and old hope, short and long term hope (Bland & Darlington, 2002, Verhaeghe et al., 2007), eroding hope (Holtslander et al., 2005), strong hope and fading hope (Duggleby et al., 2009), less hope, hope grows, new hope emerges (Holtslander & Duggleby, 2009) and initial and later hope (Verhaeghe et al., 2007). Short-term goals, or short-term specific hope, is great for affected family members who cope with their circumstances by taking life one day at a time. This hope takes away suffering and pain (Verhaeghe et al., 2007); the expectation is that when they return to 'normal' that their loved one will start feeling better (Borneman et al., 2002) or they hope just to get through each day successfully (Duggleby et al., 2009). Long-term specific hope for affected family members involves hope to achieve long term goals for both the person with problematic substance use and the affected family member (Borneman et al., 2002), hope to continue their caregiving role or seek a better job, or career or regain confidence in life (Holtslander et al., 2005; Holtslander and Duggleby, 2009). With such diversity in the types of hope and the role hope plays in the lives of people, it is vital to explore the hope experiences of family members who are caring for loved ones living with problematic substance use.

### **Turning Towards My Research**

The overall purpose of this study is to explore the experiences of hope in families affected by problematic substance use in Prince Albert, Saskatchewan, Canada. The objectives of this study are to:

1. Explore the experiences of hope in family members affected by the experience of

- problematic substance use by one of their members.
2. Delineate the impact of hope on family members affected by other members with problematic substance use.
  3. Inquire into the factors that sustain hope in family members affected by other members with problematic substance use.

### **Theoretical Framework**

In a study on hope and coping for families recovering from problematic substance use, Bradshaw et al. (2015) utilized the general systems theory as a framework. Their premise for using systems theory is that when families work together, they stand a better chance to promote and sustain each family member's health. They stated that although the whole takes precedence over the individual, any change in the family system is always preceded by a change in the individual member. As such, early stages of recovery in systems theory involve focusing on the individual family member's recovery and health which can be difficult as other family members may be struggling with their own rationalization and denial (Bradshaw et al., 2015)

In contrast, Snyder's (2002) hope theory views hope as "the perceived capability to derive pathways to desired goals and motivate oneself via agency thinking to use those pathways" (p.1). This theory links higher levels of hope with better outcomes in all spheres of life. Using this framework shifts the focus to affected family members and their wellbeing and works with them to discover pathways that motivate individual family members to sustain hope and take ownership of their lives.

The state of neglect for family members affected by substance use is largely due to a failure to appreciate the family experiences and the inability of scholars to conceptualize experiences in a manner that promotes in-depth understanding and appropriate response to the

needs of affected families. Besides neglect, family members affected by problematic substance use are often excluded from social and health care policies in addictions and a key reason for this exclusion is the lack of models of care that place families at the center (Orford et al., 2010).

One model that might be helpful in my research is the stress-strain-coping-support model. This model illustrates how stress and strain affect the lives of families as they explore coping mechanisms to move forward (Orford et al., 2013). The use of the model is appropriate for families affected by problematic substance use as it focuses on the experiences and outcomes of families. This model assumes that a close relative's substance use, causes long-term stressful life experiences for family members, thereby putting them at risk for the strain which manifests in the form of psychological and physical ill-health (Orford et al., 2010). The authors suggested that family members are not responsible for the condition of the individual with problematic substance use, but that they are exposed to stressful situations that adversely affect their lives (Orford et al., 2013).

The model has two central concepts: social support and coping. The model embraces that quality support is an invaluable asset for family caregivers, as it promotes positive health outcomes (Orford et al., 2010). From Bradshaw and colleagues' (2015) study, hope is linked to coping and the importance of self-care. When hope is integrated into the model of care, there is a possibility that affected family members will be empowered and that care will be structured in ways that support their hope.

### **Gap in Literature**

Hope has been identified as a key factor in problematic substance use and recovery (Bradshaw, Shumway, Harris, & Baker, 2013; Irving et al., 2004; Sowards, O'Boyle, & Weissman, 2006). Chadwick (2015) attributes this to the importance of hope's motivational

power to influence behaviours. Yet, it is important to note that hope and messages that inspire hope have not been empirically researched nor theoretically developed (Chadwick, 2015). Bradshaw and colleagues (2015) also observed that there is no empirical work done on the importance of hope as it relates specifically to family members and individuals using substances. Also, Schrank and colleagues (2012) discovered that though hope is an integral component of recovery, the determinants of hope are not fully understood. Chadwick (2015) also points out that few researchers have theorized the effects and components of hope appeals. As such, scholars have not fully explored the potential of hope in working with families affected by substance use.

Only in recent years, have empirical studies been carried out to examine the outcomes of hope (Marmor-Lavie & Weimann, 2006; Volkman & Parrott, 2012; Peter & Honea, 2012; Prestin, 2013), but none of these researchers have demonstrated how to formulate messages that inspire hope (Chadwick, 2015). Duggleby and colleagues (2010) made an intriguing observation in their meta-synthesis of hope. The authors observed that when family members have hope for themselves, their affected loved ones and other family members also find hope to continue with their caregiving role. Arguably, Bradshaw and colleagues' (2015) study on hope revealed that family members' focus on hope is not really on their wellbeing or recovery, but rather, on the affected individual and the expectation that individuals will recover.

### **Turning Towards Nursing**

Nurses are critical in the care of individuals living with problematic substance use and their families. Exploration of affected family member's experiences of hope will enable health professionals and especially nurses to better understand their needs and how best to support them to sustain or build hope as a self-care resource (Bradshaw et al, 2015). Health professionals need



also to understand how as an evolving construct, they can use hope to promote stability for families (Reder & Serwint, 2019). Besides, in focusing on the utility of hope in healthcare, health care providers professionals may be cognizant of the possibilities that hope can create to support decision-making (Bradshaw et al., 2015). Finally, this research has the potential to help others understand that in the face of uncertainty for families affected by problematic substance use, “hope is always warranted.” (Reder & Servient, 2009, p. 4).

### **Methodological Approach**

To explore my research question: “What are the experiences of hope in families affected by problematic substance use in Prince Albert?” I used an interpretive descriptive study design (Thorne, 2016). The interpretive descriptive design is a qualitative approach that bases its integrity of purpose on two sources: actual goals that can be utilized in practice settings and the understanding of what is known or unknown about a phenomenon based on the empirical pieces of evidence available (St. George, 2010). Interpretive description is the ideal choice for researchers searching for a straightforward description of the desired phenomenon and when they want to know more about factors in the research process: the how, when, where, what and who was involved in the research (Lambert & Lambert, 2012).

The interpretive descriptive approach is an “inductive approach designed to create different strategies to understand aspects of human health and illness experiences that have consequences for clinical context” (Teodoro et al., 2018, p. 2). Thorne’s interpretive descriptive approach aims to fill the gaps within recognizable uncertainties by interpreting the subjective experiences of participants and then form analytical themes that will be reconfigured during the analysis of the extracted data (Thorne, 2016). The foundation of interpretive description lies in doing a smaller-scale qualitative investigation of a clinical phenomenon of interest to the

discipline of nursing to capture themes and patterns, which allows for a deeper understanding of shared experiences (Thorne, Kirkham & O'Flynn-Magee, 2004).

### **Historical Basis of Interpretive Design**

Interpretive description originated from the need to have a qualitative research approach that generates a comprehensive understanding of circumstances that occur in a health practice context, thus, answering the questions within the scope of nursing and enabling the development of knowledge that supports clinical practice (Thorne, 2016). Before the development of an interpretive descriptive approach, health researchers relied primarily on existing methodologies borrowed from the social sciences to give credibility to their empirical work. Traditional methodologies demanded that the conclusion reached in studies is completely dependent on the integrity of the methods use. This led to the rigid attention to methodology and method, which became the hallmark for credible qualitative research (Sandelowski, 2014).

Although applied discipline researchers appreciated the mutually exclusive nature of the objective and subjective realities from an intellectual standpoint, the intricacies of everyday clinical practice demand that researchers attend to both realities (Stajduhar, Balneaves, & Thorne, 2001). To capture both realities, various researchers started borrowing from available traditional methodologies and blending them in their research (Thorne, 2016). Sometimes, researchers make this blending explicit in their work, which greatly disturbed qualitative researchers who felt all researches should be accountable to a unique set of standards to avoid methodological slurring (Johnson et al., 2001; Stern, 1994).

Other researchers decided to seek a variant from the conventional methodologies which have fewer governing rules and this led to the emergence of alternative methodologies like narrative inquiry, autoethnography and case analysis (Thorne, 2016). Although these

methodologies tried to legitimize research approaches that would correct the knowledge deficit of their discipline (without detracting the credibility of qualitative research content inherent in the health science community), they did not address issues specific to the nursing discipline (Maxwell, 2013).

Thorne's (2016) approach became a way to close the gap between theoretical integrity and real-life experiences. From its inception until today, nurses and professionals from other applied disciplines have discovered that an interpretive descriptive approach provides a philosophical rationale and a logical structure for a design that informs decision making in qualitative inquiries (Allgood & Fawcett, 1999; Gillespie, 2002; Paterson, Kieloch, & Gmiterek, 2001; Reimer Kirkham, 2003; Thorne et al., 2004)

### ***The Philosophical Assumptions of Interpretive Description***

Interpretive descriptive research is a powerful tool that shapes the knowledge of lived experience in the world (Lambert & Lambert, 2012; St. George, 2010; Thorne, 2016). In its social interaction context, this approach assumes that all human actions are meaningful (Garrick, 2000). However, the production of meaning needs scrutiny as it primarily depends on the authenticity of the subjective experience of the individual (Garrick, 2000; Thorne, 2016). As such, it is contestable that the individual agency and authenticity should be subjected to a greater level of doubt than what is presently obtainable.

To understand lived experiences, researchers have steered away from the empiricist/positivist research based on the assumption that participants' stories, descriptions, metaphors, and languages can be utilized to highlight what matters to them. An interpretive descriptive approach uses personal experiences as a beginning point of inquiry. It is important to keep in mind that an individual's subjective experiences are rooted in contextual and historical

understandings, making the interpretation of the lived experience a matter of deconstructing the text of the storyteller rather than a matter of individual's authenticity (Garrick, 2000; Thorne, 2016).

Another assumption in the interpretive description is that the individual is not just a passive socio-political and historical medium but has certain inert characteristics or agency which allow perception, judgment and decision- making (autonomy) to influence situations (Clark, Lissel & Davis, 2008; Garrick, 1999; Thorne, 2016). This assumption demands that researchers need to be actively involved (immersed) in the research process. The primary purpose of an interpretive descriptive study is to discover applied knowledge (Teodoro et al., 2018).

### **Utilization of Interpretive Description with Families Affected by Substance Use**

An interpretive descriptive approach is appropriate for this study because problematic substance use is a complex phenomenon with multiple uncertainties, and as a beginning researcher, I am interested in contributing to clinical practice (Thorne, 2016). Interviews are the primary data collection method used in this study. This is consistent with an interpretive descriptive approach, whereby interviews serve as a means of articulating a logical and meaningful expression of experiential knowledge (Thorne et al., 2004). In this study, I worked with data that had been collected as part of a study led by Dr. Geoffrey Maina.

The inductive approach of interpretive descriptive allows me to elaborate on the structures, patterns, and themes of the experiences of hope in affected family members (Thorne, 2016). As family members have often been excluded in social care and health policies (Orford et al., 2010), the interpretive account of family members' lived experiences creates an awareness of their plight leading to a possible change in practices and/or policies. Using an interpretive

descriptive approach leads to a logical conceptual description that revealed themes and commonalities (Thorne, 2016) that characterized the concept of hope for families affected by substance use and accounts for the inevitable variations in responses among different families.

### **Pragmatics of the Study**

The setting of this research study is the City of Prince Albert, the third-largest city in Saskatchewan, with a population of approximately 35,000. The following inclusion criteria were applied to identify eligible participants:

- Must live in Prince Albert at the time of data collection
- Able to speak in English
- 18 years and older
- Must have a family member (spouses, parents, children, siblings, grandparents, close relatives, and friends) with problematic substance
- Must not be actively using substances

Participants were recruited before I joined the study, through placing posters (Appendix A) at strategic locations around Prince Albert (Health Centers, Detoxification Centers, Emergency Department, Addiction Treatment Centers, Social Services Centers, and Walk-in Clinics), inviting affected family members who want to participate in the study to contact the researcher. A snowball sampling method was also employed by encouraging family members to use word of mouth to recruit other individuals that met the inclusion criteria. Purposeful stratified sampling was employed to identify and select participants for the interviews who are available, willing to participate and had relevant experiences (Palinkas et al, 2015; Richards & Morse, 2013). These recruitment methods ensured that there were important variations in experiences or backgrounds of participants (Palinkas et al., 2015).

### ***Data Collection***

In this study, I analyzed data that had been collected as part of a study, for which one of my Co-supervisors is the Nominated Principal Investigator (Dr. Geoffrey Maina). During the recruitment phase, family members affected by problematic substance use were invited to join in the study. A semi-structured interview guide was utilized in engaging family members; it consisted of open-ended questions and encouraged the use of unplanned probes to obtain appropriate answers (Richards & Morse, 2013). This interview format allowed for a detailed exploration of the experiences of affected family members and enough opportunity for the participants to express their thoughts. Questions were consistently structured in ways that broadened the scope of the topic and in ways that ensured participants were comfortable (Appendix B). Interviews lasted on average between 40-60 minutes.

### ***Ethics***

Ethics approval for this study was obtained from the University of Saskatchewan Behavioral Research Ethics Review Board and the University of Alberta Research Ethics Review Board. The Prince Albert Parkland Health Region provided operational approval. Informed consent (Appendix C) was obtained from each participant in writing by the person conducting the interview. All data were de-identified. The participants' data and the project's materials are stored in secured drives in the College of Nursing, University of Saskatchewan, and Prince Albert campus. The master list of participants' names and codes is stored separately from the data.

### ***Data Analysis***

Thorne (2000) identified data analysis as the most complex stage of qualitative research, yet in the interpretive descriptive design, it has received the least attention. To ensure credibility

in the analysis of this study, I used thematic analysis (Braun & Clarke, 2012, 2015). Thematic analysis is described as a method for identifying, analyzing, and interpreting patterns of meaning (Clarke, Braun & Hayfield, 2015). The thematic analysis provides systematic and accessible procedures for generating themes and codes. The thematic analysis also emphasizes the active role of the researcher in the analysis process and hinges on an organic approach to theme and coding development (Holmqvist & Frisen, 2012).

Codes are the smallest units of analysis that show special features of the data relevant to the research question. Codes are the foundation blocks (smaller units) for themes (the larger units) and form the patterns of meaning (Braun & Clarke, 2015). Themes offer a framework for reporting and organizing analytical observations. Through all the stages of the analysis, I constantly reviewed the generated themes against the coded data in NVIVO. During this process, I worked closely with Dr. Maina, Dr. Ogenchuk and another Research Assistant.

Thematic analysis can be used to identify patterns across and within data concerning the participants' lived experiences, behaviours, and practices, as well as perspectives (Braun & Clarke, 2012, 2015). Thematic analysis is used to analyzed small and large data sets (Cedervall & Åberg, 2010; Mooney-Somers, Perz, & Ussher, 2008) and reflect both heterogeneous and homogenous participants populations. Thematic analysis can be utilized for both deductive (theory-driven) and inductive (data-driven) analyses to capture both latent (underlying) and explicit (manifest) meaning. Using thematic analysis ensured that an auditable, rigorous, and systematic analytical process was carried out (Clarke, Brown, & Hayfield, 2015) to enhance the credibility of my study.

## ***Rigor***

Trustworthiness, rigor, or truth value in qualitative research is defined as the degree of confidence that a researcher has in the data, methods, and interpretation utilized to ensure the quality of a study (Pilot & Beck, 2014). Although researchers have debated over the years on what constitutes trustworthiness in qualitative research (Leung, 2015), five components of trustworthiness as outlined by Guba and Lincoln (1994) and cited by Cope (2014) are generally accepted by qualitative researchers. These include credibility, transferability, dependability, confirmability, and authenticity.

**Credibility.** Credibility is defined as the confidence one has in the truth of the research (Connelly, 2016), the participant's perspectives and how the researcher interprets and represents these views (Cope, 2014). Credibility is enhanced by the researcher's ability to describe their experiences and verify the study's results with participants. For this study to be deemed credible, readers who share similar experiences should be able to easily recognize the description of the experiences in this study (Cope, 2014). To achieve this, a reasonable sample size of 21 participants with a purposeful sampling method was used to ensure participants have a wealth of lived experience. The raw data and field notes are kept for future reference. I transcribed the data to reflect the participants' experiences in their own words.

**Transferability.** Transferability refers to the study's findings that can be applied to other groups or settings (Cope, 2014; Houghton, Casey, Shaw, & Murphy, 2013). To ensure transferability, a rich description of the study context and population must be provided, so that readers can assess if findings are transferable (Thomas & Magilvy, 2011). However, the criterion of transferability depends on the purpose of the study and is only applicable if the study's



purpose is to generalize some of the findings (Cope, 2014). In this study the primary purpose was exploratory.

**Dependability.** Dependability is defined as the stability or constancy of the research data over time and across similar phenomena (Polit & Beck, 2012, 2014). An audit trail was kept by allowing for an extensive description and review of the logistics of the study from the beginning to the end (Thomas & Magilvy, 2011). Describing in detail the design, the research team, the recruitment, the interview, the transcription procedures, and the analysis procedure which was detailed ensured the integrity of this study (Williams & Morrow, 2009).

**Confirmability.** Confirmability refers to the ability to show that the findings are a representation of the participants' perspectives and not the researcher's viewpoint or biases (Cope, 2014) or the degree to which the study results can be repeated (Polit & Beck, 2014). I ensured confirmability by describing how the interpretations and conclusions of findings were established and illustrating that the findings reflect the original data (Cope, 2014). To ensure this, I used extensive quotes from participants. I also involved multiple people during the development of the coding framework. This included the involvement of patient and family advisors, who were volunteers with lived experiences.

**Authenticity.** Authenticity refers to the degree to which the researcher completely expresses the emotions and feelings of the participants' experiences. It is necessary to do this in a faithful manner (Polit & Beck, 2012), which includes showing the range of various realities and communicating the participants' lives in a realistic way (Polit & Beck, 2014). I used direct quotes of participants in reporting my findings so that readers can understand the essence of the participants' experiences (Connelly, 2016).

## **Limitation of the Study**

The perspective of those who volunteered for this study may differ from other affected family members who for some reason did not want to participate in the study. There is a possibility that those who came forward to participate feel more empowered to speak about their experiences, feel less stigmatized, or have found ways to make meaning of their experiences.

Due to the multidimensionality and complexity of problematic substance use in Prince Albert, the unbiased perspectives and experiences of all family members or their needs may not be captured. While the study falls within the primary purpose of the larger research study, I was not directly involved in the collection of data and therefore might not recognize all the nonverbal expressions of the experiences under study. Hope began to emerge as a key theme during the data analysis of the project and shaped my proposed study. Hope was not the initial focus of the study for which the data I utilized was collected, rather it became apparent through inductive analysis. It would have been helpful to structure interviews entirely around experiences of hope and hopelessness to gain an even deeper understanding of the phenomena.

## **Significance**

Hope is known to influence individuals to survive against all odds and when absent, death may be imminent (Miller, 2019). As such, this study contributes to the understanding of how families affected by problematic substance use experience hope, and how its utility as a coping mechanism (Miller, 2019). Through this research affected family members may have discovered their need for hope, apart from the hope they have for the person engaged in problematic substance use (Duggley, 2010). This could have fostered confidence and a reawakening to make positive changes that could improve their quality of life and enhance their

ability to effectively support the person engaged in problematic substance use (Bradshaw et al., 2015).

The family's active participation in the care of individuals with problematic substance use aligns with one of the key goals of the Mental Health and Addiction Action Plan for Saskatchewan, relating to the creation of individual and family-centred services for affected family members (Winder, 2014). Giving hope and supporting affected family members also aligns with one of the goals of the Mental Health Commission of Canada (MHCC, 2012) which is to offer everyone hope, the possibility of recovery, supports families, and promotes the best possible mental health and well-being for all Canadians. Given the link between hope and well-being, it is important to better understand how hope is experienced and can be supported.

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## **Chapter 2: Manuscript**

**Title of Paper:** Exploring the experiences of hopelessness and hope in families affected by problematic substance use.

**Authorship:** Udoh, G., Maina, G., Ogenchuk, M. & Caine, V.

**Journal:** Journal of Family Nursing

**Abstract**

**Hope is a central concept in the helping professions.** While there is no consensus about its definition, the multidimensional and multifaceted nature of hope is acknowledged. In this qualitative interpretive descriptive study, the experiences of hope for 21 family caregivers of individuals affected by problematic substance use are explored. As hope and hopelessness are two powerful forces that co-exist in the human realm, this study inquired into hopelessness to better understand hope experiences. The findings revealed three major themes: the manifestation of hopelessness, the impacts of hopelessness, and factors countering hopelessness. Family cohesiveness, social structures, and the interplay of hope and hopelessness were discovered to be significant factors that determine hope for family members of individuals who experience problematic substance use. The findings support evidence that despite the stress of caring for individuals with problematic substance use, family members can sustain hope. Appreciating caregivers' challenges gives health care professionals a better understanding of how to assist families to find hope during uncertain and difficult times. Nurses can assist families to identify their strengths, identify agencies, and pathways of hope, which can support their self-care and enhance their resiliency.

**Keywords**

Family, problematic substance use, hope, hopelessness, interpretive descriptive

**Exploring the experiences of hopelessness and hope in families  
affected by problematic substance use.**

Families are an integral part of people's lives and problematic substance use by a family member can have significant impacts on the physical, spiritual, emotional, and psychological

well-being of a family (Smith & Estefan, 2014; Smith, Estefan & Caine, 2018). These impacts affect family ties making family members feel hopeless. Hopelessness within the context of problematic substance use arises when families feel helpless to mitigate the effects of substance use, including the relational, financial, physical, or occupational impacts. Hopelessness is exacerbated as few formal supports for family members exist (Herzanek, 2015). Problematic substance use by one member of the family can destabilize family dynamics and relationships and can result in other members engaging in maladaptive behaviour like denial or overlook the behaviour of the affected member (Howard et al., 2010). The ensuing loss of family equilibrium and the resultant stress calls forth a sense of disempowerment, which constrains the family's ability to support the affected person (Orford, Velleman, Natera, Templeton, & Copello, 2013).

While family members often play multiple roles in the lives of people with problematic substance use, the ability to empower family members to cope well is challenging as there are often few or no resources to support their self-care or caregiving role (Conyers, 2009; Orford, Copello, Velleman & Templeton, 2010). Affected family members require respectful and supportive services to create a sense of 'normal' and reduce the stigma they may experience (Haskell et al, 2016). In this interpretive descriptive study, an inquiry is made into the experiences of family members affected by problematic substance use with attention to their experience of hopelessness and hope.

## **Literature Review**

### **Situating Families**

Problematic substance use is one of the greatest single mental and public health crises in modern society, and it affects individuals from all walks of life (Darrodi, Younesi, Bahrami &

Bahari, 2010; Khantzian & Albanese, 2008). Affected family members endure painful and stressful experiences (Conyers, 2009) brought on by problematic substance use (McCann, Lubman, Boardman & Flood, 2017). Yet, few studies have inquired into the support that would be helpful for affected families (Conyers, 2009; Orford, Copello, Velleman & Templeton, 2010). Families often feel disempowered due to their inability to sustain meaningful family relationships with an individual with problematic substance use. Maintaining relationships with individuals with problematic substance use is difficult because such individuals often prefer social exclusion instead of active engagement. This may be occasioned by their experiences of stigmatizations and victimization (Nunes & Sani, 2013). At the same time advances in the study of problematic substance use and neuroscience have increased the understanding of the neurobiological changes that occur when individual transitions from social or recreational substance use to problematic substance use (Uhl, Koob, & Cable, 2019). Affected families often need adequate support for self-care, socioeconomic support, psychosocial resources, and support to enhance their coping mechanisms to maintain their wellbeing and quality of life (Orford, Velleman, Natera, Templeton & Copello, 2013).

Families are a source of physical, emotional, social, and financial support to family members who are using substances. Also, they are a vital anchor during difficult periods of dealing with problematic substance use treatment and periods of remission (Smith, Estefan & Caine, 2018). Therefore, there is an urgent need to identify and mobilize families' inherent strengths and resources to build a strong network of healthy relationships, which can support family members affected by problematic substances use.

## **Impacts of Problematic Substance Use**

Problematic substance use is a family disease (Bradshaw et al., 2015), which threatens the families' homeostatic relationships. Affected families often experience anxiety due to the changes caused by living with an individual with problematic substance use (Bradshaw et al., 2013). The stress and shift in the equilibrium of the family's relationships are often triggered by role confusion within the family. Family roles are destabilized because the individual with problematic substance use is no longer able to function as expected in their role due to their emotional needs (Grant & Ferrell, 2012). As such, other family members often take over the affected individual's role or perform multiple roles to maintain a functioning family unit. This dysfunctional role dynamic can have grave consequences on family members' physical and psychological health status (Weisner, Parthasarathy, Moore, & Mertens, 2010), and can lead to problematic substance use and depression (Akram et al., 2014). Besides, affected family members are at an increased risk of poor mental health, marital problems, and declining parental capacity (Compello et al., 2006). Moreover, affected family members can experience high levels of relationship dissatisfaction and conflict, sexual dissatisfaction, and/or psychological distress (Kloesteman & O'Farrel, 2013). Physical exhaustion, sleep deprivation, anxiety, and emotional distress brought on by desperation and frustration can be but a glimpse of the experiences of affected families (Bradshaw et al., 2015; Conyers, 2009; Rane et al., 2017). Therefore, it is vital to assist affected family members to sustain hope to mitigate the negative impacts of problematic substance use.

## **Turning Towards Hope**

Hope has been identified as a resource to assist families affected by problematic substance use to regain control over their lives (Bradshaw et al., 2015) and as a key psychosocial

element for caregivers (Duggleby et al, 2010). Yet, few studies exist that explore hope as a way of supporting families affected by problematic substance use (Orford et al., 2013). The concept of hope is inherent in the field of positive psychology whose primary focus is happiness and hinges on three constructs: positivity in person, experience, and social structures (Fu, Chen, Li & Zhu, 2018). When these three constructs are positive, negative situations and perspectives tend to transform into positive ones in human lives (Seligman, 2011; Fu, Chen, Li & Zhu, 2018). Various studies have broadly been done on the significance and the meaning of hope in both the social and health care field (Koehn & Cutcliffe, 2012; Williams et. al., 2013). It is in recent years that researchers have started focusing on caregivers' needs of individuals affected by problematic substance use (Akram, Copello, & Moore, 2014).

Even though hope plays a vital role in people's lives (Kim, Kim, Schwartz-Barcott & Zucker, 2006), it is difficult to operationalize hope or find a standardized definition of hope. There is no consensus on the definition of hope (Cutcliffe & Kaye, 2002; Herrestad, Biong, McCormack, Borg & Karlsson, 2014; Samson, Tomiak, Dimillo, Lavigne, Miles, Chowuette & Jacob, 2009). One possible definition of hope, which accounts for its richness, complexities, and multidimensional nature was proposed by Farren, Wilken, and Popsvich in 1992 (as cited by Sampson et al., 2009). These authors define hope as a construct with four processes: rational, spiritual, relational, and experiential. Despite the lack of consensus on the definition of hope, there is an agreement that hope is elusive, yet dynamic in nature and a powerful resource for life (Cleary, Sayers, Lopez, Shattell & Cleary, 2016; Miller, 2019). Samson and colleagues (2009) caution that a comprehensive definition of hope must consider hope's evolving reality and the cognitive, behavioural, and spiritual dimensions. When defined in relation to problematic

substance use, hope is about doing something with greater confidence and to move past distress (Kimball, Shumway, Austin-Robillard & Harris-Wilkes, 2017).

Most studies on hope demonstrate that hope has both cognitive and emotional components. Cognitively, hope is the interaction between anticipation and wish while emotionally, hope is the difference between the negative emotions one feels when unable to meet an expectation and the positive emotion one feels when expectations are met (Fu et al., 2018). Hope can be approached in different ways: holistically, it can be approached as a specific and generalized hope (Fu et al., 2018; Szabat, 2020). The former being personalized needs or specific expectations or goals while the latter refers to a generalized optimistic future perspective or a future orientation without any related events (Szabat, 2020). Based on the type and nature of goals to be achieved, hope can be classified into two dimensions: active and passive. The former involves actions taken to actualize the goals and the latter being an inactive state of waiting for things to take a better turn. Interestingly, Fu and colleagues (2018) discovered that individuals start with generalized hope, but due to the diagnosis, course of treatment, probability of recovery, and other uncertainties, they tend to shift to specific hope. However, Szabat (2020) posited that the nature of hope demonstrates that its therapeutic value is a vital and indispensable resource for humanity.

### **Theories of Hope**

Over the last two decades, the world has seen the development of theoretical hope models that have widely influenced the field of positive psychological research (Weis & Speridakos, 2011), two of which have been applied in the healthcare field. Snyder's (2000) hope theory is the most acceptable in psychological research. Snyder (2000) argues that hope can be categorized into pathways and agency related hopeful thoughts. He views hope as "the perceived capability

to derive pathways to desired goals and motivate oneself via agency thinking to use those pathways" (p.1). This theory links higher levels of hope with better outcomes in all spheres of life. Recently, Snyder's hope theory has been applied to psychotherapy and it has led to the development of some strategies, which can systematically increase hope in clients.

Just like Snyder, Herth perceived hope as a goal and motivational attainment (Herth, 2001). However, unlike Snyder, Herth is mainly concerned with an individual's goals as they relate to one's ability to cope with interpersonal loss, medical illness, and other kinds of psychological stressors (Weis & Speridakos, 2011). Herth developed his hope theory with three dimensions that correlate with a client's psychosocial functioning. The first dimension of Herth's theory is conceptually like Snyder's dimension of agency thinking. This dimension refers to people's ontological view that they can realistically achieve their desired goals (Arnau, Martinez, Guzman, Herth, & Konishi, 2010). Herth's second dimension is the affective-behavioural dimension of hope which is also like Snyder's component of the pathway; it portrays individual's confidence that their actions and plans will culminate into goal achievement (Arnau et al., 2010). The third dimension of Herth's hope theory is called the affiliative-contextual dimension. This refers to an individual's perceived spiritual support, sense of belonging and social support. Herth's model has been utilized in the medical and nursing fields to guide interventions to improve the quality of life and coping mechanisms of individuals with terminal and serious illnesses (Kylma et al., 2009; Schrank, Stanghellini, & Slade, 2008). To understand the dimensions of hope and its effects on individuals, the relationship between hope and hopelessness needs to be understood.



## ***The Interplay of Hope and Hopelessness***

Hope and hopelessness are powerful experiences that coexist in the human realm (Flaskas, 2007). The interplay of hope and hopelessness within close relationships and family ties can be very complex because each family's experiences are embedded in historical and familial contexts and the wider social and community processes (Flaskas, 2007). Therefore, to understand the hope experiences of affected families, their family history, familial relationships, and the community that they are part of, should be taken into consideration. When presented in this manner, Herrestad and colleagues (2014) observed that hopelessness, which tends to thrive in challenging circumstances when the future is uncertain and bleak, will no longer thrive, but give way for hope to be cultivated. Therefore, it is important to recognize that "strong hope and strong hopelessness [can] exist side by side" (Flaskas, 2007, p.189).

### **Purpose and Objectives**

This study is part of a larger research study<sup>5</sup> that looks at the experiences of families affected by substance use and their ability to access resources. A related aspect of the study, which became evident during the data analysis, is on the experiences of hope and hopelessness in families affected by problematic substance use. It is important to note that the interview guide was not structured to delve deep into the subject of hope and hopelessness in the context of living with a member with problematic substance use. Hope, which began to emerge as a key theme during the inductive data analysis, is the focus of this paper. The specific objectives of this paper are to:

1. Explore the experiences of hope in family members affected by substance use.

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<sup>5</sup> The larger study is study entitled: *Exploring the needs of and developing resources for families affected by addiction in Prince Albert, Saskatchewan*. Dr. Geoffrey Maina is the Principal Investigator of the Study. The overall purpose of his study was to explore the experiences and needs of families affected by problematic substance use and to develop culturally appropriate and family-centered resources to address them.

2. Delineate the impact of hope on families affected by substance use.
3. Inquire into the factors that sustain hope in families affected by problematic substance use.

### **Setting the Context of the Study**

The geopolitical landscape of mental health and addictions care informed by the narratives that the participants in this study shared their experiences with problematic substance use. Prince Albert, with a population of 36,000 has the highest per-capita alcohol use in the Province, which is also twice the national average (Fenno, 2016). There is also a significant problem with injecting drug use which is depicted by the high consumption of clean needles (CRISM, 2018). Prince Albert also has the highest HIV prevalence of 3.5 times that of the national average (Leo, 2015). The inadequate resources to manage problematic substance use in the community, such as detox, inpatient treatment services, outpatient services, etc. is well documented (Maina et al., 2017). Despite high substance use in the region, the city does not have a safe injection site though there have discussions on the establishment of one. Hence, harm reduction services remain underdeveloped.

### **Methodology**

An interpretive descriptive design was utilized to address the objectives of this study, as it places the focus on the experiences of family members, as well as ensures that the study has relevance to practice (Thorne, 2016). The study followed the interpretive descriptive stages outlined by Thorne (2016) which are: comprehending the concept, synthesizing the relationships, theorizing the inferences, and re-contextualizing the knowledge gained. Interpretive description was utilized as it explores the knowledge of lived experiences (Lambert & Lambert, 2012; St. George, 2010; Thorne, 2016) and “has an inductive approach designed to create different

strategies to understand aspects of human health and illness experiences that have consequences for clinical context” (Teodoro et al., 2018, p. 2). This study design also assumes that the individual is not just a passive socio-political and historical medium, but has certain inert characteristics that allow perception, judgment, and decision making (autonomy) to influence situations (Clark, Lissel & Davis, 2008; Thorne, 2016).

## **Methods**

This research study is in the City of Prince Albert, the third-largest city in Saskatchewan, Canada with a population of approximately 36,000 with a metro population of 43,000 (World Population Review, 2020). Data collection was facilitated through a semi-structured interview guide with open-ended questions and the use of unplanned probes (Richards & Morse, 2013). Purposeful stratified sampling was employed to identify and select 21 participants. The length of the interview was between 40-60 minutes. Interviews were audiotaped and later transcribed verbatim.

### ***The Rigor of the Study***

The credibility of this study was maintained by using purposeful sampling to select participants who had a wealth of lived experiences. Patient/ family advisors were invited at every stage of the research process to provide insight and advice to guide the research, including the analysis. Member checking was also utilized to ensure that the data collected was a true reflection of what the participants said. Dependability was maintained through a code- recode procedure to ensure data were coded in the same manner over time. Confirmability of the study was shown by discussing ideas with the research team to explore if they have a similar understanding and interpretation of the ideas before using them. Describing how the analysis was done, how the interpretations and conclusions were reached also enhanced the confirmability of

the study. Finally, authenticity was demonstrated by using direct quotes of participants to report the findings.

## **Findings**

In this study, participants came from a variety of backgrounds (the demographic descriptions of participants are presented in Table 1). In total, 21 family members were interviewed. In the analysis of the interviews, major categories, and themes within the affected family members' experiences of hopelessness and hope were identified. The major themes included: a) manifestations of hopelessness; b) impacts of hopelessness and c) countering hopelessness.

### **Theme 1: Manifestations of Hopelessness**

Individuals react differently to stressors in their lives. While some individuals show overt signs of distress and adversity, others endure and conceal all emotions. In this study, emotions of hopelessness were manifested in various forms: a broken heart, depression, frustration, helplessness, repressed anger, resignation to fate, and sadness. Families experienced broken heartedness as they were deprived of functional relationships, or when their dreams and hopes for their loved ones affected by problematic substance use were shattered. Some family members reacted by feelings of shame, self-blaming, and regret. One participant commented:

*So, the dreams I had for [my son] fell by the wayside. They had to go because it was not going to be, for this new [person]. The new person, with the illness and struggling with addiction as well. So, I had to let go of that. And I had a lot of, this sounds strange, but I had envy of people who could talk about their children with such pride, not that I was ashamed of [my son]. They would talk about, oh 'he is an engineer now' and 'he's got his*

*three children and they're going to school and doing so well'. And [my son] could not maintain the relationship, so I have a lot of grief in those years. (44-year-old female)*

Parents of adult children that lived with problematic substance use found themselves providing care and nurturance to their grandchildren. As a result, they experienced a reversal of parent-children roles, a situation that also complicated normal family dynamics. Often, such families bore the burden of concern for their adult children living with problematic substance use and their grandchildren. Rather than enjoy retirement, families with adults struggling with problematic substance use traded retirement to assume parental responsibilities for their grandchildren, a paradoxical situation that was described frequently in this study. One grandmother recalls:

*I used to allow her [my daughter] to visit, but then I was worried about my daughter getting into stuff or being around people that I did not know. They are always around other people that are on drugs as well, and that was scary for my granddaughter. I do not allow that anymore. She can phone, she can come to our house and visit if she wants to see her, and my granddaughter knows that. (62-year old grandmother)*

Parental problematic substance use was reported to have significant mental health impacts on their children. Such parents were said to struggle with discharging parental responsibilities such as the provision of security, nurturance, and warmth. Adolescents who grew up in homes with problematic substance use engaged in maladaptive and at times self-destructive behaviours such as self-harm as a way of dealing with adverse childhood experiences. Below is a reflection from a participant of her experiences as a teenager.

*We moved so much I did not really have any friends, not close friends. And, so the addiction plus the abuse (at home) made me shy away from people, it just made it very*

*difficult for me to make friends, from that and then from not staying in one place, we only stayed in one place for one month. So yes, it really impacted me. Depression, I considered suicide more than once, I attempted more than once. (45-year-old female)*

Emotional dysfunction was another feature of living with or caring for an individual with problematic substance use. To show a sense of normalcy, affected family members concealed their emotional state or distress to others. They hid their sadness, hurt, and unintentional neglect behind a facade of smiles and laughter while feeling hopeless inside. Because of the suppressed emotions, affected family members frequently experienced outbursts of anger, and lied to cover up their state. These maladaptive behaviours further engendered a negative and disruptive atmosphere marked by mistrust and uncertainty about the state of the loved ones, thus compounding their sense of hopelessness. The unpredictable behaviour of the individual caused fear and anxiety within the family as parents endeavoured to protect and support their affected children.

*He's (father) scared to come home at night because now she's (sister) suicidal and always that she has no hope and she has, nothing left to live for and she's hopeless, she's almost hit bottom but not enough to get help and threatening suicide. So now when Dad does leave the house he wants to leave the house to get away from her so he doesn't have to sit there and watch her but yet then when he's away from the house he's scared to home cause he's scared he's gonna find her hanging in the garage cause she keeps, that's what she keeps saying is she's going to hang herself in the garage. (44-year-old female)*

The social, economic, relational, physical, and mental impacts of problematic substance use and the uncertainty around recovery were disheartening to many families. The loss of

relationships within the family disrupted family dynamics and equilibrium, causing undue stress and worry about the individual using substances and the impact problematic substance use has for the family. Excessive worrying became a manifestation of the hopelessness they experienced.

*I used to feel like that all the time, I used to worry. I used to just wait for a knock at the door from the police telling me she was gone. But then I was thinking to myself, "I can't live like that." And I cannot help her (her daughter), she does not want my help even though I work in the field of addictions and mental health. I have tried helping her, but she does not want my help and I know I cannot help her. I worry I am worried if she is alive, I am worried if she has enough to eat, I worry where she is sleeping. It was like that for years and years and then I told myself, "I can't be doing that to myself 'cause I'm gonna get sick." I said, "I need to help myself. (62-year old grandmother)*

Family members felt overwhelmed, emotionally drained by constant vigilance, anxiety, desperation, and the frustration that they experience daily. Affected family members often experience harm to their social, financial, physical, and emotional wellbeing. Persistent anxiety and worry about their safety, their loved one's health, and a sense of an uncertain future often compound their fear about the functioning of their family unit.

## **Theme 2: Impact of Hopelessness**

Living with a sense of hopelessness has a tremendous impact on family relationships. Hopelessness evokes deep emotions like desperation, frustration, helplessness, and resignation to fate. These emotions can disrupt the family relationships leaving unbearable pain behind. Families affected by problematic substance use experienced frustration, which was attributed to a perceived lack of commitment to the family and an inability to provide financial security due to problematic substance use. Although affected families retain hope that the family member with a

problematic substance use issue would recover or at least be functional, this hope was betrayed because of relapse. Couples with dependent children were especially hard hit by the dysfunctionality that problematic substance use caused them.

*When I was pregnant with the twins, he relapsed for the first time. And, then six months went by and he relapsed again, and then it was three months and then it was two months and then he was drinking monthly, and then he was drinking weekly. And so it went right back, it took time, but it went right back to how it was. And, meanwhile, we had two little people who were three, four, five, you know so the strain of all of that, uhh, the pain of all of that. (50-year old female)*

Some family members harbour deep-seated anger against family members with problematic substance use, who were deemed to be the source of the family misfortunes such as loss of meaningful relationships, or financial security. The inability to provide parental love and nurturance was a common consequence of problematic substance use. Children living in a home where problematic substance use was prevalent were compelled to seek love in what was described as ‘wrong’ places and ‘wrong’ relationships. As children, they were often vulnerable to adverse childhood experiences that led to substance use.

*Absolutely. I felt neglected. I felt unwanted, unloved. I always wish I had somebody else's parents because all my friends had loving, caring, kind parents and I did not have that. That is something I envied. I wanted somewhere to belong, I wanted somebody to love me, and where I found that love was in the drugs and alcohol scene. It numbed the pain; I escaped reality through the drugs. I went from guy to guy to guy, trying to fill that void and that emptiness in me with sex and relationships, and I would allow guys to beat me, use me, and sell me because I didn't know. I wanted to feel worthy. I wanted to feel loved.*



*I searched all over for a place to belong. A lot of that – my mom’s gambling and my dad’s drinking – was a result of that neglect and whatnot. I lived most of my life in fear.*

(27-year old female)

Despair was another impact of living in a home with problematic substance use. Often, affected families expressed feeling as though they were at the ‘end of their rope’ having tried all they could to assist their loved one with problematic substance use.

*She [my sister] was 13 when she got into it. She got involved with gangs. Every other night, there was something flying through the window. She flew through the window a few times from men throwing her through the window or her fighting. She would come home battered and bleeding and bloody and stuff from fighting. Always breaking into places and bringing the stolen stuff to our house. That too, you know. We were always in danger, always in danger. My brother, my older brother, did not. He was actually a pretty good kid. He had good friends, he played hockey, he was never home, I think, because of that. (27-year old female)*

When the possibility of recovery from substance use vanishes or is farfetched, family members tend to resign to fate about the eventual demise of their loved ones or the diminished possibility of recovery. Others sever their relationship with the affected individual, for fear of enabling them or to protect their wellbeing. Without even realizing it, many participants appeared emotionally disconnected by describing the severing of relations with the member with problematic substance use.

*I know it sounds cold, so I washed my hands of him because I have given so much to try and help him. So much of my life that there is nothing else I feel that I can do. I cannot*

*put more time and effort into helping him if he does not want to help himself. I have lost a brother because of drugs and alcohol. (38- year old female)*

Family members feel helpless as they constantly worry about their loved ones. Even when people with problematic substance use stop using substances, there is deep worry about a possible relapse. Problematic substance use can create a sense of disempowerment for the affected family members, thereby constraining their ability to assist their loved ones. Family members affected by problematic substance use also reported feeling overwhelmed due to the caregiving burden. Some are so consumed that they neglect their self-care as this mother expressed:

*We become so consumed because that is all you think about. You will neglect the other part of your family because you are so consumed with what that child is doing. You're wondering, "Where are they? Are they safe? Are they sleeping? Are they eating? Did they... Are they alive?" Whatever it is. You are so consumed. (57-year old female)*

The sense of powerlessness can increase the risk of developing depression. This dampening of the mood was commonly expressed in situations involving intergenerational problematic substance use.

*This intergenerational addictions and dysfunction it's like a train and you can't stop it, you try, everything like I, I put my kids through, we went to family treatment, and they all went to individual treatment when they were teenagers so, it's like a, it's just like you just can't stop it, I don't know what you do. (57-year old female)*

The experiences of helplessness, hopelessness, depression, wanting to give up, though commonly expressed in the narratives of participants were not present all the time. Participants

also reported being hopeful and optimistic about the circumstances they found themselves. Therefore, it was apparent that moments of hopelessness and hope sometimes coexisted.

### **Theme 3: Countering Hopelessness**

Countering hopelessness demands a multifaceted approach that includes breaking the silence, creating a safe place, identifying a safe person, having knowledge on early detection of problematic substance use, access to resources, and making amends. Due to knowledge deficit, stigmatization, feelings of guilt and shame associated with problematic substance use, affected family members need access to diverse resources that will help them make sense of what it means to live with a member with problematic substance use and promote and sustain hope. Finding resources for support is ongoing for individuals, families, and communities and though difficult at times, begins with breaking silence, which keeps families from speaking out about their social situation. Silence is often deployed as a protective mechanism and to preserve the positive image that individuals may have in the community. It is only in speaking out, that their problems will be known. Families affected by addiction may need help to break the silence about their circumstances for cathartic and support purposes.

*Getting people to talk about their feelings, getting your support system whether it's friends that are healthy or loved ones that are healthy that you can talk to and bounce things off. Having a sense of spirituality helps, whether it is praying, going to church, the cultural side, going to sweats, or something like that. I have always believed in the holistic wheel: mental, physical, emotional, spiritual. And if you do one or two things in each area, it helps you as a person. So, I think supporting families is giving them the hand, helping them out, letting them talk about their issues, showing where we can refer them if need be and that. (50-year old man)*

Counsellors who knew how to support families affected by problematic substance use were deemed as safe people. Such individuals can provide undivided attention and create a safe space for families to express their emotions regarding the impact of problematic substance use.

Affected families can pursue a special relationship with such counsellors, some even becoming a safe person or a lifeline.

*I would call my sponsor and talk about it. I literally had to have a life coach, which I call my sponsor today, before I made any kind of decision, to call her and run it by her first. I needed guidance, side-by-side, walk, and hold my hand. I am thinking back now if I were a kid and I needed that help, I don't know where I would even begin to look. (27-year old woman)*

In the pursuit of self-care, family members sought different support services and resources. These include spiritual support, support groups, or an online group where affected families receive help and support to understand addiction and pursue self-care. Sharing experiences with people with similar experiences brought them hope and helped them to remain positive about the future.

*I found love when I got to AA, because of the fellowship. They loved me until I was able to love myself. Hugs every day, hanging out every day, keeping contact every single day about everything, feelings, every time I got triggered or angry. I'd call my sponsor and talk about it. I literally had to have a life coach, which I call my sponsor today, before I made any kind of decision, to call her and run it by her first. I needed guidance, side-by-side, walk, and hold my hand. (27-year old woman)*

Helping professionals such as health professionals, addiction counsellors, teachers, and social support workers are well-positioned to be allied with affected family members through early

detection, education about the impact of problematic substance use, and anticipating the resources that these individuals may need. Experiences of families affected by addictions need to be validated by helping professionals during therapeutic encounters. Such interventions can have a significant impact on engendering hope among families affected by addiction.

*The first resource needed is an early intervention or somehow, someone or some group of people, who are going to catch the early signs you know. Not wait until it is so serious that the children are apprehended but that the earlier signs. I do not know how that would work and how to have a resource like that, but it's needed. So that is one thing I can think of. Hm. I think all the professional people have more education about addiction and the effects on the family. (63-year woman)*

Affected families may not always appreciate the impact that problematic substance use has on their wellbeing. Hence, they may not access the resources that they need to live well. Others may opt not to reach out for help because of shame and silence that stigmatization and the fear of not wanting to betray family members who have problematic substance use can bring. Living in a community where problematic substance use is present, health care providers should, therefore, anticipate and proactively provide support for affected families.

*Being able to find easier access to these services, whether it is counseling services or whatnot. To have easier access to some of these programs, maybe Al-Anon or 12-step programs. Addiction runs rampant in City A in general. I think having more information and having those more easily accessible would be beneficial. That also, for NA and AA, they have public information people that are supposed to be doing that. I do not know if they are doing their job or not. (28-year old man)*

Peer interventions are critical in supporting families affected by problematic substance use. Sharing lived experiences and strategies to mitigate the impact of problematic substance use to a family can have a profound impact on families. Families with such lived experiences can empathize and understand affected families and can offer practical advice on how to navigate crises caused by problematic substance use. Shared experiences empower both the recovered and the individual living with problematic substance.

*I found a 12-step support group that helped me on my path to recovery. I surrounded myself with positive people that I met in the group, and I attended that program for years – I still do attend those meetings. They taught me how to live and they taught me basic skills. I got my kids back – I had another child in the time I was out there experimenting. I changed my whole life around and I have that experience. I can relate to others out there, so that's why I'm in this field today: to help others and to show others that there's a way out. (27-year old woman)*

In this research, participants indicated varying relational impacts of problematic substance use on family dynamics. While some relational ties were irreparably damaged due to problematic substance use, making amends was a way for other individuals with the problematic substance used to address the pain they may have caused. Seeking reconciliation and forgiveness within families was made possible with increased insight into the impact of problematic substance use to a family and taking responsibility for them. Such an approach tends to bring healing and hope to them and the ones they hurt. Families discovered that forgiveness restores relationships by releasing them from guilt and shame. Yet, making amends is a difficult undertaking.

*No, I just know I need to make amends because I stole from my sister, I hit her, I stole from my brothers, I did a lot of shady things to my family and my mom too. I tried to*

*attack her when I was high, and I tried to steal money, and I stole her car. I was the black sheep. I did not have a family and they all stuck together. I was out there wandering and existing, but I had a lot of resentment towards my mom and dad for that, for being ashamed of me and calling me down every day. I got called every name in the book: whore, slut, everything. A lot of pain there, but I have healed over the years and I am at that point, now, where I forgive them. But, now, I need to do my part and apologize to them for all the things I did to them. It is still under repair. I'm not close to them. (27-year old woman)*

Families need diverse resources to promote and sustain hope and to counter the impact of hopelessness. Thus, there is an urgency to recognize that supporting family members is key to helping the person with problematic substance use.

### **Discussion**

From the study, it was apparent that living with a family member with problematic substance use threatened family cohesion, and induced a lot of stress that if unmitigated, made affected family members vulnerable to physical and mental health conditions. The change in the individual with problematic substance use creates an imbalance in the family's functioning that makes the affected family members seek ways to restore the equilibrium (Bradsaw et al., 2013). Affected family members tend to compensate for the one with problematic substance use due to the interconnectivity existing within family ties (Richardson, 2012). When the equilibrium of the family is destabilized by substance use, family members start to experience a sense of hopelessness.

Though some feel like giving up on their loved one as they have tried everything with no success, they still feel obliged to support or connect due to family ties. Ambivalent feelings of

both strong positive traits like love, encouragement, care, admiration, and strong negative traits like disappointment, rage, frustration, wish for separation are often experienced by family members simultaneously (Weingarten, 2007). Experiences of anxiety, desperation, frustration, or depression were not uncommon because of caring for and living with a family with problematic substance use. Families felt increasingly hopeless especially if resources to support the member with problematic substance use were lacking. Yet, involving family members in addiction treatment of their loved one can have a profound impact on their sense of hopefulness (Duggleby et al., 2010). Moreover, due to the stigma in the social environment about an individual living with problematic substance use, family members sometimes experience social exclusion which may impede their desire to break the silence, reach out to seek support (Stockdale et al., 2007). This exclusion pushes the family further into maladaptive behaviours like living in denial, taking the blame for the substance abuse, deflect the pain they are experiencing through the use of humour, suppressing their feelings, or making excuses for the individual affected (SAMHSA, 2019; Stockdale et al., 2007).

Problematic substance use creates a sense of uncertainty about how to act, how to make sense of the problem. Although the experiences of living with a family with problematic substance use are unpredictable, the degree to which a family member will experience hope or hopelessness is often determined by factors such as family background, and the social network surrounding the affected family. Giving up on or over-involvement in the lives of individuals with problematic substance use were two strategies that affected family members commonly employed. These strategies were informed by a perceived probability of recovery from problematic substance use with the resultant restoration of relationships and functionality.



Since participants drew on the knowledge of locally available addiction resources to foreground these lived experiences, recovery, and restoration of normality narratives were, significant determinants of experiences of hope and hopelessness. Moreover, since participants relied solely on these narratives, and given the realities of their geographical location, they were bound to be disappointed or disillusioned.

To prevent maladaptive behaviour due to undue stress and maintain their psychosocial and emotional stability, some participants made use of counselling services. Involvement in the treatment for the individual with problematic substance use generated hope and families took life one day at a time, waiting to see the outcome (Holtzlander & Duggleby, 2009). Possessing such a hope took away some of the pain and suffering as there is an expectation that the individual living with problematic substance use will soon be better or will recover. Conversely, when the individual relapses or refuses to seek assistance for recovery, hope eroded or faded away (Verhaeghe et al., 2007).

With support, affected families can have long-term hope for themselves and move forward in life to achieve their goals despite their loved one's problematic substance use. Though the situation among families affected by problematic substance use can appear bleak, it was evident in the experience of participants that finding hope or courage to move forward does not lie in imagining alternatives, but to accept the fact that often there is no specific discernable alternative. Therefore, the findings of this interpretive descriptive study suggest that hope of families of people living with problematic substance use is a dynamic experience marked by uncertainties.

Family members' hope fluctuates and is influenced by family cohesiveness, social structures that exist within the families, and recognition that hope and hopelessness are always

present in families. The ability of affected families to sustain hope is dependent on the hope pathway and agency they choose and the degree of the uncertainties they experience (Duggleby et al., 2010). To ensure that the agency and pathway align, affected families can be encouraged and supported to set personalized, meaningful, and realistic expectations which they believe are achievable (Hellman, Worley, & Munoz, 2018).

The lack of consideration of substance use as a chronic illness or a concurrent disorder had a tremendous impact on the way families generated and sustained hope. For many, they were focused on the recovery of the loved ones, while they did not attend to how living with problematic substance use affected them. Hence, they did not entertain a need for self-care because of living with or caring for an individual with problematic substance use. Moreover, since harm reduction services are not well-developed, affected family members did not entertain the idea of a possibility that recovery or abstinence does not need to be the immediate goals. This informed how hope and hopelessness were manifested and expressed.

### **Practice Implication**

Although hope and hopelessness are distinct constructs, they are correlated (Flaskas, 2007). Hope can act as a resilience construct that buffers the grievous impact of hopelessness. Health care providers need to recognize the interplay between hope and hopelessness, as byproducts of living with an individual with problematic substance use. By practicing self-awareness, health professionals can help families sustain and nurture hope for family members. Moreover, recognizing hope-hopelessness tensions that manifest in families affected by problematic substance use, health professionals can assist families to locate hope pathways that can work for them (Duggleby et al., 2010).

Health professionals can also support affected families to shift their focus from specific goals of curative options to the present responsibility that they have. Health professionals can encourage affected families to develop agency thinking to sustain hope and understand and regularly undertake hope assessment (Fu et al., 2018). Given that family members did not articulate an understanding of problematic substance use as a chronic illness, affected families need the education to increase their understanding of the complexities of problematic substance use. Besides, affected families need support to locate social support to provide material assistance, information, and emotional support to maintain their health and wellbeing; such support can enhance their quality of life (Orford, Velleman, Natera, Templeton & Copello 2013).

Health care providers also need to recognize that children who live with parents or guardians with problematic substance use suffer from adverse childhood experiences, which have a tremendous impact as they grow up. Thus, health care providers can act as advocates for families affected by problematic substance use.

### **Limitations**

As a convenient study, the perspectives shared in this project may not capture the totality of the impact of living with or caring for an individual with problematic substance use. Due to the stigma surrounding substance use, there is a possibility that some critical voices were silenced as a result. Due to the multidimensionality and complexity of problematic substance use in Prince Albert, the unbiased perspectives and experiences of all family members or their needs may not have been captured. The interview guide was not structured to delve deep into the subject of hope and hopelessness in the context of living with a member with problematic substance use as hope began to emerge as a key theme during the initial data analysis of the project.

### **Future Research**

This study is a secondary analysis and the interview questions were structured to elucidate answers for questions about locating resources for families affected by addiction. Hope was one of the themes generated during the analysis, There's a need to engage in studies that focuses on hope, including strategies of fostering hope, or minimizing hopelessness or intervention study that focus on hope in relation to family cohesiveness in families affected by problematic substance use. Doing a separate study will then structure the interview questions around these topics.

### **Conclusion**

The findings of this study resonate with previous research findings of the importance of hope for caregivers, but the findings offer a new perspective on hope specifically for family members of individuals with problematic substance use. Affected family members experience multifaceted effects on their family dynamics and safety, physical, financial, and emotional wellbeing, a persistent sense of hopelessness, and uncertainty about the future. The findings highlight the actions and impacts of hopelessness and the use of hope as an important coping resource for families. Findings have implications for nurses and other health professionals working with families affected by problematic substance use. Healthcare providers need to help locate individualized hope agencies and pathways in families, which will sustain their hope in ever-evolving circumstances.

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**Table 1: Participants; demographic information**

| Identifier | Age | Gender | Ethnicity    | Marital status | Family member(s) affected by problematic substance use |
|------------|-----|--------|--------------|----------------|--|
| PA.001     | 44  | F      | Caucasian    | Married        | Sister   |
| PA.002     | 56  | F      | Caucasian    | Married        | Brother  |
| PA. 003    | 48  | F      | First Nation | ?              | Children   |
| PA.004     | 57  | ?      | First Nation | ?              | Daughter   |
| PA 005     | 57  | F      | First Nation | Single         | Siblings and 4 children                                |
| PA.006     | 28  | M      | First Nation | ?              | Father and 3 sisters                                   |
| PA.007     | 27  | F      | Indigenous   | Married        | Sister, 2 brothers and mother                          |
| PA.008     | 50  | F      | Caucasian    | Married        | Spouse, father and 2 brothers                          |
| PA.009     | 37  | M      | Metis        | ?              | Brothers and parents                                   |
| PA.010     | 50  | M      | Caucasian    | Divorcee       | Ex-Wife and 2 children                                 |
| PA.011     | 54  | M      | First Nation | Married        | Children   |
| PA.012     | 45  | F      | Metis        | Married        | Cousin   |
| PA.013     | 63  | F      | First Nation | Widow          | Son  |
| PA.014     | 37  | ?      | Metis        | ?              | 2 sisters  |
| PA.015     | 38  | F      | Caucasian    | ?              | Brother  |
| PA.016     | 30  | F      | Indigenous   | Single         | ?  |
| PA.017     | 72  | M      | Caucasian    | Single         | Daughter and grandson                                  |
| PA.018     | 32  | M      | Asian        | ?              | Father   |
| PA.019     | 22  | F      | Caucasian    | Single         | Brother  |
| PA.020     | 62  | F      | First Nation | Single         | Daughter and granddaughter                             |
| PA. 021    | 35  | F      | First Nation | ?              | Sister and brother                                     |

### Chapter 3: Conclusion

In this chapter, I take a reflective turn and revisit the reasons for undertaking this study. I am mindful that I engaged in this work for personal, practical, and social reasons. While I have come to new understandings about hope, there is also much that still needs further exploration. I was excited when the possibility opened to be part of a larger study entitled *Exploring the needs for and developing resources for families affected by addiction in Prince Albert, Saskatchewan* that was led by Dr. Geoffrey Maina. Being part of a team in which I could learn to undertake research was significant to me. I remember the meeting where we began to look more closely at the emerging themes from the interviews - that day hope was one of the themes that became visible. It was at that moment that I could sense the positive contributions that I could make to the study and to better understand the experiences of families, who have a member who is affected by substance use.

As I reflect on the personal, practical, and social reasons to undertake this work, I also am reminded of Carper's (1978) four ways of knowing. In this chapter, I will make visible how my ways of knowing have made me more humble as I imagine new ways of working with families affected by problematic substance use. Carper (1978) also draws my attention to the nurse's self-awareness of their weaknesses, strengths, and biases - all of which impact the nurse-patient relationship. Turning towards practice, I can see the importance to take on an attitude of cultural humility to understand that cultural and social practices are fluid and ever-changing. I increasingly try to view issues from the families' perspective (Fisher-Borne, Cain, & Martin, 2015). Through the empirical way of knowing utilized in this research, I now understand that hope and hopelessness are experienced differently by each family and by each member of the family. The knowledge gained from this study has also encouraged me to think about the

aesthetic ways of knowing. It is here that empathy matters, and that I understand that problematic substance use is a problem that is storied by the social worlds people live within. This new understanding has motivated me to try and assist families in ways that foster and sustain hope, instead of being judgmental.

### **Personal Implications**

My early memories of growing up are filled with chaos as my dad was living with problematic substance use. At the time neither I nor my mother and siblings had any knowledge of problematic substance use. We did not know how to deal with my dad's intermittent angry outbursts. We did not realize that my dad needed help, as well as all of us in the family. After spending several years reflecting on this, I believe that the reason for this ignorance was that alcohol was and still is socially acceptable in the community I grew up in. As such, while I grew up, there were no treatment centers my dad could access, there was no education or place to go to for support, and no one to discuss problematic substance use with. The only resource that saw us through those very difficult years was my mom's undaunted belief that all will be well no matter the difficulties. Living one day at a time was my mom's motto to give us hope. She lived and exemplified hope to us. Her hope was sustained by a focus on us and her belief that we can make our way in life. It is through the study that I can more clearly see that hope was critical in our life as a family and that hope was future oriented.

Many years later, I started a group for single parents in the community I lived. I observed that most of the women who attended the group were grandmothers. Many of the grandmothers who joined were taking care of their grandchildren as their children were living with problematic substance use. These grandmothers were constantly asking me for directions on how to raise their grandchildren as they had little or no support. As well, they had many questions on what to

do when their children are in crisis and how to support them. I struggled to provide answers to their questions, and I felt helpless not knowing how to empower them. During those times, I often wondered about the social responsibilities of individuals within families. I also wondered what motivates people to help others, despite the extraordinarily difficult circumstances.

Based on my growing up experiences of seeking to understand problematic substance use and my desire to know more so that I can assist the single mothers and grandmothers in my group, I decided to undertake this research. Now that I have completed this research, I can see how much I did not know and how so much of my understanding was shaped by approaching problematic substance use from a place of deficit. During this research, I learned that the presence of hopelessness does not negate the presence of hope. I learned that both hope and hopelessness can exist side by side (Flaskas, 2007). This explains why my mother was able to sustain hope and despite the hopelessness, we found ourselves living as a family. In this current study, I also become much more wakeful to the understanding that problematic substance use is not just an individual disease, but that it is a family disease (Bradshaw et al., 2015). Family members' lives are so intertwined with the individual affected that it is very difficult for them to extricate themselves from the individual with problematic substance use. I now understand why the grandmothers were unable to 'just' cut themselves off from their children. Each member of the family compensates for the one individual affected by problematic substance use, due to the interconnectivity that exists among family members (Richardson, 2012). In retrospect, I can see that I needed to work with them to discover hope pathways and agencies that work for them to achieve their goals and provide them with resources that can help them sustain hope and maintain their self-care. The recognition that hope was important seemed intuitive for my mother.

## **Clinical Implications**

I currently work in the community as a home care nurse. In my role as a clinical coordinator, I supervise nurses and act as a resource person for nurses while they are working in the field. Working in the community can be very challenging as nurses must work as independent practitioners and oftentimes resources are not readily accessible. We are asked often to see patients with mental health concerns including substance use issues, who are discharged from mental health units into community settings. I and most of the home care nurses I supervise, do not have the mental health background to deliver quality care to these patients and their families. We often struggle to understand these patients. Several patients have community treatment orders and these orders often create a sense of dread for nurses. At times, I hear some nurses saying: “I am not comfortable visiting these clients and they are so unpredictable. Please can you give me some of your clients and take these visits from me?” Often the nurses who work with clients who have a community treatment order find themselves in the middle of a family crisis or they see the patient as being resistive to care.

Without a background in mental health and addictions, I always feel so incompetent to answer their questions and provide the necessary support that they need to be confident in their role. Besides the nurses, the family members of these clients often call the office seeking educational resources, support, and clarification on issues about their loved ones affected by substance use. I was called to engage in this research to gain knowledge and insights and a strong sense of responsibility to be confident in my supervisory role. From my research, I have come to appreciate the experiences of family members of those living with problematic substances and what sustains them. It is because of the study that I now realized that nurses are strategically placed to act as educators, advisors, and advocates for their patients and their families.



### *Nurses as Educators*

Participants in this current study spoke about their need to learn more. For nurses to be good educators to patients and families living with problematic substance use, the nurse needs education first. The need to educate health professionals aligns with the Mental Health Commission of Canada's strategy of "increasing training for frontline professionals and raising awareness in workplaces to reduce stigma surrounding mental illness and increase an individual's likelihood of accessing care when they need it" (MHCC, 2017, np). After completing my study, I strongly believe that nurses must have knowledge about hope and hopelessness to assist families affected by problematic substance use.

It is also important for nurses to realize that family members are more likely to be diagnosed with their substance use with higher medical claims and costs (Ray et al., 2007), and five persons in close relationship with a person with problematic substance use will be affected by a problematic substance use with grave consequences (Bisetto Pons, González Barrón, & Botella Guijarro, 2016). In response to this knowledge, nurses need to ask family members detailed questions about how their caregiving role is affecting their emotional lives and their wellbeing. It was evident in the study that watching a loved one affected by problematic substance use without knowing the illness is very alarming to family members due to fear of the unknown. Therefore, nurses need to be prepared to educate families on the etiology, pathophysiology, neuroscience, treatment, and resources available to assist individuals living with substance use and their families to reduce the fear they are experiencing and foster hope. Due to the multifaceted issues associated with problematic substance abuse, nurses also need a sound ethical background to educate families to make informed decisions that will empower them and their loved ones. According to Carper (1978), when a nurse makes an ethical decision,

it should be free of personal biases and based on the experience of clients. If biases are present, this may cause moral distress to the nurse and the obligations to clients conflict (Campbell, Penz, Dietrich-Leurer, Juckes, & Rodger, 2018).

### *Nurses as Advisors*

It was evident in the study that family members are often not listened to. Yet, recognizing that problematic substance use is not an individual, but a family disease (Bradshaw et al., 2015) necessitates that nurses include family members in care. This is important, as family members who have insights into their loved one's condition can offer important information that can influence treatment decisions and care for the person affected by problematic substance use. Family members' participation in care is vital in reducing mortality and morbidity due to problematic substance use. As the goal of nursing in the 21st century is family-centred care, family participation in care will promote holistic care delivery resulting in positive outcomes for all members of a family.

To promote family participation, nurses need to incorporate the family system theory into their approach to care which encourages families to evaluate their closeness, emotional processes, distance, to stay away from blaming, and the issues which are still unresolved from their family of origin (Haefner, 2014). Encouraging family participation also aligns with the goals of the Mental Health Commission of Canada which is to offer everyone hope, the possibility of recovery, and promotes the best possible mental health and well-being for all Canadians (MHCC, 2012). The framework of the commission for mental health is based on the principle that individuals' family members and circle of support must be placed at the center of change for success to be achieved when addressing problematic substance use (MHCC, 2012). There is also a need to identify and treat problematic substance and concurrent mental illnesses

because they are associated with greater adverse effects than treating either illness alone (Abrams & Sher, 2016; McKee, 2017).

### ***Nurses as Advocates***

Nursing advocacy is so vital to nursing practice that it is included in the nursing code of ethics framework (Hanks, 2008). The mandate for social justice advocacy is visible in the ethical framework of the nursing profession. Therefore applying emancipatory ways of knowing (Chinn & Kramer, 2017) in the care of problematic substance use will provide an accessible lens to demonstrate how social justice can be implemented by nurses while removing social structures that can impede social change (Peart & MacKinnon, 2018). As the healthcare system is becoming more complicated to navigate due to fragmentation, high technological use, complex health insurance policies, health legislations, and government policies, family members find it difficult to access the health system for services. To increase the accessibility of health care services to affected family members, nurses have an obligation to advocate for them. This is important as families of people affected by problematic substance use are often excluded from care arrangements and lack accessible and meaningful resources. Nurses need to advocate for family members who have been observed to be excluded from care (Orford et al., 2010). Family member's active participation can enhance family relationships and promoting recovery (Darrodi et al., 2010). This aligns with one of the goals of the mental health and addiction *Action Plan for Saskatchewan*, which includes the "recognition and support of family members and caregivers as part of the service team" (Stockdale Winder, 2014, p.13). This support will be a foundation for service providers to promote family involvement thereby encouraging their ability to advocate for their loved ones.

When nurses apply the ways of knowing in relation to emotional intelligence, cultural literacy and individualized and family-centred care, the negative image that the public has concerning problematic substance use can be partially mitigated and affected family members can be empowered in their caregiving roles. Nurses can employ research to identify hope as a variable in building the resiliency of families affected by problematic substance use.

### **Social Implications**

Family and individual experiences of hope and hopelessness are embedded in historical and familial contexts and the wider social and community processes people live within (Flaskas, 2007). This too holds for nurses. Nurses need to be culturally competent (Thackrah & Thompson, 2013) to elucidate and foster hope for affected families as each family's needs are different depending on their historical and socio-cultural position. While respecting an individual's rights, nurses need to understand that their beliefs and values can infringe on these rights and seek to promote a healthy relationship with clients and their families (Rane et al., 2017).

There is also a need for emotional intelligence for nurses as they work in an emotionally charged atmosphere where emotions impact patient care decisions and influence professional relationships (Smith, Profetto-McGrath, & Cummings, 2009). As such, nurses need to be aware of their strengths and biases, learn to think before acting, withhold judgment until adequate information is obtained, be able to perceive issues from other people's point of view and the ability to manage the relationship with others by harnessing their own and other people's emotions to maintain a good relationship (Raghubir, 2018). Overcoming personal bias and reaching out to assist these families to overcome their challenges, will provide a firm foundation

for emphatic health care without which, health care system will continue to fail in meeting the needs of these affected families that feel neglected (Kendall & Barnett, 2015).

There is a need to involve community leaders and groups in a collaborative effort to help family members sustain their hope and make sense of their experiences of hopelessness. Mobilizing leaders in the community aligns with the mental health commission of Canada's sixth strategy which is to: "mobilize leadership, improve knowledge, and foster collaboration at all levels" (MHCC, 2012, p. 11). For nurses to create a positive impact on problematic substance use, they need to engage in sociopolitical ways of knowing (White 1995). The use of socio-political ways of knowing is key to addressing the needs of vulnerable people like individuals living with problematic substance use and their families. As such, nurses are encouraged to go beyond victims/perpetrators' concepts, to norms, practices, and legislation that can be changed to producing outcomes that include and empower vulnerable groups like families affected by problematic use (Lu, 2019). This sense of activism also plays a role in fostering and sustaining hope.

### **Conclusion**

Although hope is seen as a way for families to regain control over their lives (Bradshaw et al., 2015) and influences individuals to survive against all odds, no studies have inquired into the experiences of hope for families with problematic substance use (Bradshaw et al., 2015). This study has contributed to our understanding of hope and hopelessness. As recommended by MHCC (2012), "reducing stigma is important for changing how people think, but addressing discrimination, upholding rights and eliminating structural barriers are critical for changing how people act" (p. 23). Therefore, helping families affected by problematic substance use to overcome stigmatization, break the silence of secrecy, uphold self-care and sustain hope

demands a collaborative effort between the government, the health sector, the private sector, the community, and individuals. If this effort can help families understand that hope is about possibilities within uncertainty, their caregiving role will be empowered, self-care will improve, and their resiliency will be enhanced.

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## Appendix A: Poster for Recruitment

College of Nursing  
University of Saskatchewan



### **PARTICIPANTS NEEDED FOR RESEARCH ON**

**Research study title: Exploring the needs of and developing resources for families affected by addiction in Prince Albert, Saskatchewan!!!**

We are looking for participants who have a loved one that lives with any type of addiction to share their experiences on how they are impacted by the addiction.

You can choose to be interviewed as an individual or as a group.

Individual interview shall last 40-60 minutes;

Sharing circle/focus group discussion, comprising of 8-10 participants will last between 60-80 minutes.

**Participants will receive a \$ 25 dollar Tim Horton's gift card as a token of appreciation!!**

For more information about this study, or to volunteer for this study, please contact:

Dr. Geoffrey Maina  
214-1301 Central Avenue, Prince Albert,  
Saskatchewan, S6V 4W1  
tel: 306-765-3887  
Email: [geoffrey.maina@usask.ca](mailto:geoffrey.maina@usask.ca)

This study has been reviewed by and received approval through the Research Ethics Office at the University of Saskatchewan.

**For further information about this research, you may contact the** Behavioural Ethics Board at;

**Room 223 Thorvaldson, 110 Science Place,  
Saskatoon SK S7N 4J8  
Phone: 306-966-2975**

Email: [ethics.of](mailto:ethics.of)



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## Appendix B: Interview Guide



**Research study entitled:** *Exploring the needs of and developing resources for families affected by addiction in Prince Albert, Saskatchewan.*

**Researcher(s):** Dr. Geoffrey Maina, Assistant Professor, College of Nursing, Prince Albert Campus, 214-1301 Central Avenue, S6V 4W1. Tel- 306-765-3887; Dr. Marcella Ogenchuk, Co-Principal Investigator, University of Saskatchewan, marcella.ogenchuk@usask.ca, Tel: 306-966-1757

### Guiding Questions

1. Demographic information
  - a. Name, age, ethnicity, occupation?
  - b. How would you describe yourself?
  - c. Any information that is relevant to substance use and addiction?
  - d. What were your growing up experiences?
  - e. Past experiences with substance use?
2. Loved one affected by addiction
  - a. What type of addiction does he/she contend with?
  - b. History and trajectory of addiction?
  - c. Family involvement in addiction treatment of the loved one?
3. Impact of addiction
  - a. Impact of addiction on the loved one?
  - b. Impact of addiction on the family?
  - c. How has addiction in your family affected you?
    - i. Socially
    - ii. Financially
    - iii. Physically
    - iv. Psychological
    - v. socially
4. Do you consider yourself in need of professional help to deal with addiction in your family?
  - a. If so, what type of help?
  - b. Have you sought professional help to deal with addiction in your family?
5. Do you have any needs that you would like to be met to help you deal with addiction in your family?
6. What resources might you need to live well and support your loved one living with addiction?

- a. How would they look like?
- b. What should we include?

## Appendix C: Consent Form



### **Participant Consent Form for individuals with loved ones that live with addiction**

You are invited to participate in a research study entitled: Exploring the needs for and developing resources for families affected by addiction in Prince Albert, Saskatchewan.

**Researcher(s):** Dr. Geoffrey Maina, Assistant Professor, College of Nursing, Prince Albert Campus, 214-1301 Central Avenue, S6V 4W1. Email: geoffrey.maina@usask.ca, Tel- 306-765-3887

Dr. Marcella Ogenchuk, Co-Principal Investigator, University of Saskatchewan, marcella.ogenchuk@usask.ca, Tel: 306-966-1757

### **Purpose(s) and Objective(s) of the Research:**

This project aims to explore the needs of families affected by addiction and to develop resources that can help families with people living with addiction live well. The objective of this study is to improve the well-being of families affected by addiction, by providing them with meaningful resources to care for themselves and for their loved ones that are affected by addiction. This study entails participating in a one-time individual in-depth interview lasting between 60 to 80 minutes. Anyone with a loved one who struggles with the addiction of any kind is eligible to be included in the study.

**Procedures:** You have been asked to participate in the study because you have indicated that you have a loved one such as a brother or a sister, a spouse, a parent or a close friend that is living with a form of addiction. This study entails participating in an in-depth interview that will be between 60-80 minutes in length. The interview will be audio recorded for transcription later. The interview shall take place in a private space of your choice or within the setting that will be identified by the research team. The interview will focus on your experiences living with and provide care and support for a loved one who lives with addiction. We will also explore how addiction in your family affects you and investigate the kind of resources that can help you deal with issues that arise from having a loved one in addiction.

This project has been funded by the Saskatchewan Health Research Foundation.

**Potential Risks:** Participating in this study carries the possibility of stress from reliving difficult experiences with family members that live with addiction. To mitigate such distress, professional counselors will be on standby to provide counseling services. Also, researchers will work with counselors affiliated to the health region during the life of the project to provide support, debriefing and counseling services.

**Potential Benefits:** This study will help the research team to develop a resource to support families affected by addiction.

**Compensation:** A 25-dollar Tim Horton Gift card will be provided.

**Confidentiality:** No one will know if you have participated in the study because your name will not appear in the transcription or publications that will arise from this research. We will use a false name whenever a quotation from the interview is used in the publication or report. The research team will endeavour to maintain the confidentiality of the participants. However, we have a duty to report any threats to the safety of an individual or children in need of protection.

**Storage of Data:** Audio recordings of the interviews will be stored in a password-protected computer. Transcriptions of the interviews will be password protected, and a hardcopy of the interview transcripts will be kept in a locked filing cabinet. Consent forms will be stored separately from the transcripts in a locked cabinet so that it will not be possible to associate a name with any given answer. Data collected from this study shall be used in conference presentations, and in manuscripts for publication. Hardcopies of the transcriptions will be shredded, and electronic copies of audio records will be destroyed after five years and in accordance with the University of Saskatchewan policy.

**Right to Withdraw:** Your participation is voluntary, and you can answer only those questions that you are comfortable with. You may withdraw from the research project, at any time without giving any reason. You will still receive compensation in full even if you withdraw from the study. You will have an opportunity to review the transcript within the first month following the interview. You can withdraw your data within a month of your participation in the interview by contacting the researchers using email or phone numbers provided in this letter. After this date, it is possible that some form of data analysis will have already occurred, and it may not be possible to withdraw your data.

**Follow up:** Participants will be invited to a workshop where the findings of the study will be disseminated. Participants may also contact me to obtain the results of the study.

**Questions or Concerns:** Contact the researcher(s) using the information at the top of page 1. Please note that this research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board.

Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

## **Consent**

### **SIGNED CONSENT**

Your signature below indicates that you have read and understood the description provided.

I have had an opportunity to ask questions, and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

|                     |           |       |
|---------------------|-----------|-------|
| _____               | _____     | _____ |
| Name of Participant | Signature | Date  |

|                        |       |
|------------------------|-------|
| _____                  | _____ |
| Researcher's Signature | Date  |

The space below is to be used if you would like to give oral consent.

|                     |                        |       |
|---------------------|------------------------|-------|
| _____               | _____                  | _____ |
| Name of Participant | Researcher's Signature | Date  |